FORMALISING REMINISCENCE WITHIN LONG-STAY CARE SETTINGS: EARLY LESSONS ON METHODS AND MATERIALS FROM DARES

DementiA education programme incorporating ReminiscencE for Staff (DARES)

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The DARES study…

- DARES is a clustered randomised controlled trial with an embedded qualitative component.
- DARES aims to evaluate the impact of a structured education reminiscence-based programme for staff (SERPS) on the quality of life of residents with dementia.
- Staff (nurses and health care assistants) within clusters allocated to the intervention arm will receive the SERPS.
- Staff within clusters allocated to the control arm will deliver usual care.
- Sample Size
  - 18 long-stay units
  - 17 residents with dementia per unit
  - 10 staff per unit
  - Total 306 residents and 180 staff
- Blinded outcome measurement will be undertaken at baseline and at 22-25 weeks post randomisation.

Challenge #1: Defining reminiscence

We define reminiscence as the deliberate use of prompts, for example photographs, smells, music and questioning, to promote the recall of pleasant memories. We view reminiscence as a one-to-one interaction between the person with dementia and a staff member, except in the case where working in a small group is appropriate as determined by the capacity and needs of the individual with dementia. Reminiscence may be spontaneous, i.e. the opportunistic use of reminiscence while delivering nursing care or planned i.e. where reminiscence is the specific focus of the intervention. The aim of using reminiscence with people with dementia is to stimulate the person, provide enjoyment and foster a sense of achievement and self-worth. The anticipated outcomes of using reminiscence are improvement in the person's quality of life, behaviour and mood.

Challenge #2 - Outcome measures

- ***Primary:***
  - Quality of life (Quality of life-AD, QOL-AD)
- ***Secondary:***
  - Agitation (the Cohen Mansfield Agitation Inventory, CMAI)
  - Depression (the Cornell Scale for Depression in Dementia, CSDD)
  - Staff attitudes to residents with dementia and perceived care burden (Strains in Dementia Care Scale, SDC-scale)

Challenge #3: Diagnosis of dementia

- Diagnosis will be determined in any of the following ways:
  - A formal diagnosis of dementia determined by the DSM-IV criteria for dementia.
  - Any other diagnosis of dementia by a medical clinician.
  - Resident is on anti-alzheimers medication.
  - Nursing records and/or nurses' judgement that the person has dementia.

Challenge #4: Gaining assent from participants with dementia

- The research assistant will work to obtain assent from each potential resident with dementia :
  - The RA will spend time building a rapport with each potential participant and will then briefly explain the study and explore with the resident whether s/he is interested in being included.
  - The RA will give written information about the study to potential resident participants with whom a rapport has been established and to the next of kin.
  - If the resident says ‘no’ or indicates he/she is not interested in participating in the study…
  - If the resident agrees to have the study explained further …
  - If the resident expresses interest in the study the resident will be assumed to have assented.
  - This process will be used on each occasion data is collected. Assent will continue to be assessed throughout the study.
  - In instances where it is not possible to gain consent or active assent directly, consent by proxy will be used, where the older person’s next-of-kin will be asked to give formal written consent on behalf of the research participant. The next-of-kin will be asked to make their decision on the basis of their knowledge of the individual’s prior attitudes and values.

Challenge #5: Developing the SERPS

- NICE (2003) define structured education as “a planned and graded programme that is comprehensive in scope, flexible in content, responsive to an individuals clinical and psychological needs and adaptable to his or her educational and cultural background”

- Components of a structured education programme:
  - An explicit philosophy
  - A structured curriculum
  - Trained educators
  - Quality assurance
  - Audit

Overview of development of SERPS

- **Informing stage:**
  - Literature review on reminiscence, definition and implementation, content analysis of dementia educational programmes
  - Concept analysis of ‘reminiscence’
  - Qualitative interviews with experts (n = 9), staff (nurses and HCA) (n = 18), family (n = 5) and people with dementia (n = 3).
  - Broad themes: consider context, recommendations for content, understanding dementia, dealing effectively with challenges, knowing the person.
- **Development stage:**
  - Structured Education team determined programme structure, devised content and drafted materials
- **Review stage:**
  - Reviewed by the DARES core team
  - Reviewed by experts (n = 3)
  - Feedback incorporated into the programme
  - Pilot (minor modifications made following delivery)

SERPS Content

Day 1:

- ***Session 1:*** Introduction/Setting the scene
- ***Session 2***: Understanding the person with dementia
- ***Session 3****:* How memory works
- ***Session 4***: Reminiscence Explained
- ***Session 5***: Communicating with person with dementia

Day 2:

- ***Session 6:*** Behaviours that challenge
- ***Session 7:*** Using reminiscence in practice
- ***Session 8:*** Person-centred care planning for people with dementia

Day 3:

- What has happened, record sheets, life story book, care plan

Delivery approach

- Consistent with our philosophy, aiming to empower participants
- Interactive strategies e.g. identify shared goals, scenarios, practice examples, experiential approaches
- Supported by handouts, video clips and resources
- Life history book
- Reminiscence triggers!!

Example

Scenario: To support exploration of participants' attitudes and understanding of dementia and introduce the concept of unmet needs and PCC.

During her shower:
Mary: I'm cold, I'm cold (shivering and trying to cover up)
The nurse checks the water and finds that it is warm.
Nurse: The water is fine Mary. We're nearly finished, just a few more minutes. The shower will make you feel better.
She continues on showering Mary. Mary lashes out when the water splashes on her face.

Discuss this situation in your group. Are there other reasons (apart from Alzheimer's) to explain why Mary is reacting as she is? Is the nurse's behaviour triggering Mary's behaviour? Suggest the group imagine themselves as 'Mary'

Challenge #6: Supporting, quality assurance, audit

- SERPS delivered by a core team to ensure consistency in delivery
- Set a baseline: defined how often and what type of reminiscence work to engage in (in line with our definition)
- Support visit 3 weeks following Day 2 of the programme (audit form devised)
- Action plan devised if necessary
- Day 3 - 6 weeks after Day 2 of the programme
- Contact telephone number

Initial feedback pilot

- Site 1: Ten participants (or five dyads comprising of a staff nurse and health care assistant) completed the programme.. All participants completed the evaluation form. Participants indicated that programme content was relevant and practical (always n = 10), clear and understandable (always n = 10) and covered what they needed to know (always n = 9, mostly, n = 1). They described the pace of the programme 'as right' (always n = 8, sometimes n = 2) and the activities and tips helpful (always n = 10). All participants reported that the sessions prepared them to implement reminiscence (always n = 10).
- Site 2: Nine participants (four dyads plus an additional staff member) completed this programme. All participants (n = 9) indicated that programme content was relevant and practical, clear and understandable and covered what they needed to know. They described the pace of the programme 'as right' and the activities and tips helpful. All participants reported that the sessions prepared them to implement reminiscence.

What they said …

Content

- Participants' commented favourably on content:
  - “(I have) a better understanding of what we deal with dementia and how to deal with any problems that may arise and what actions to take.”
  - “(It was) helpful to know about individualised care.”
  - “The session help(ed) to improve skills and practice.”
  - “(It was helpful to know) how to deal with aggression.”
  - “Background information and explanation of Alzheimer’s Disease which helped to create awareness and understanding about dementia and how reminiscence can help the resident (was helpful).”

Delivery

- Participants commented favourably on the ‘active” approach to delivery:
  - “I felt that the active learning and involvement of the whole group was an excellent way of getting us to learn and think about reminiscence.”
  - “The practical work we did (was helpful). The activities we did (was helpful).”
  - “The programme was delivered in a very relaxed manner. Participation was always welcomed from us, our opinions always seemed to be appreciated.”

No recommendations for change were made.

Participant reported “looking forward” to implementing reminiscence.

Audit

- Participants in both sites documenting life histories and implementing reminiscence
- The life history work had resulted in participants uncovering new knowledge about residents.
- Reminiscence was making a difference to communication, staff/resident relationship and resident agitation
- Examples of innovation and creativity.
- Reminiscence structured around individual needs
- Involvement of others families, other residents, staff
- Seems to work best when number of staff involved and a committed manager

Lessons learnt

- The diagnosis of dementia is an issue in long-stay care settings.
- Attention must paid to giving the person with dementia a voice.
- A reminiscence education programme must address wider issues e.g. dementia how it affects the person, person centredness, unmet needs.
- Knowing the person's story is central to reminiscence.
- A need to strengthen links between 'knowing the person' and 'planning care'.
- Staff motivated and committed to making changes.